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ABSTRACT

This guide was developed to introduce families of young children with disabilities to the early intervention system. It describes early intervention services and defines the roles and responsibilities of parents and practitioners. The guide uses a question and answer format to present information on the following topics: (1) what is early intervention?; (2) why are there programs and services for families and babies?; (3) whom does early intervention help?; (4) who refers children to early intervention services?; (5) what does early intervention offer families?; (6) what can families offer early intervention?; (7) who pays for early intervention services?; (8) what information will the early intervention service provider need to help the child?; (9) why is an assessment needed?; (10) what happens during an assessment?; (11) why does an early intervention program need the parents' help?; (12) why is an early intervention team used?; (13) what happens during the Individualized Family Service Plan (IFSP) planning time?; (14) what will be in the IFSP?; (15) who may be providing early intervention services?; (16) how can the service coordinator, infant specialist or teacher, speech/language pathologist, occupational or physical therapist, social worker, and psychologist help?; (17) what early intervention services may be offered?; (18) what will happen during home visits?; (19) what is in the child's file?; (20) what are procedural safeguards and privacy?; and (21) what kinds of programs and services are available for the child after his or her third birthday? (JDD)

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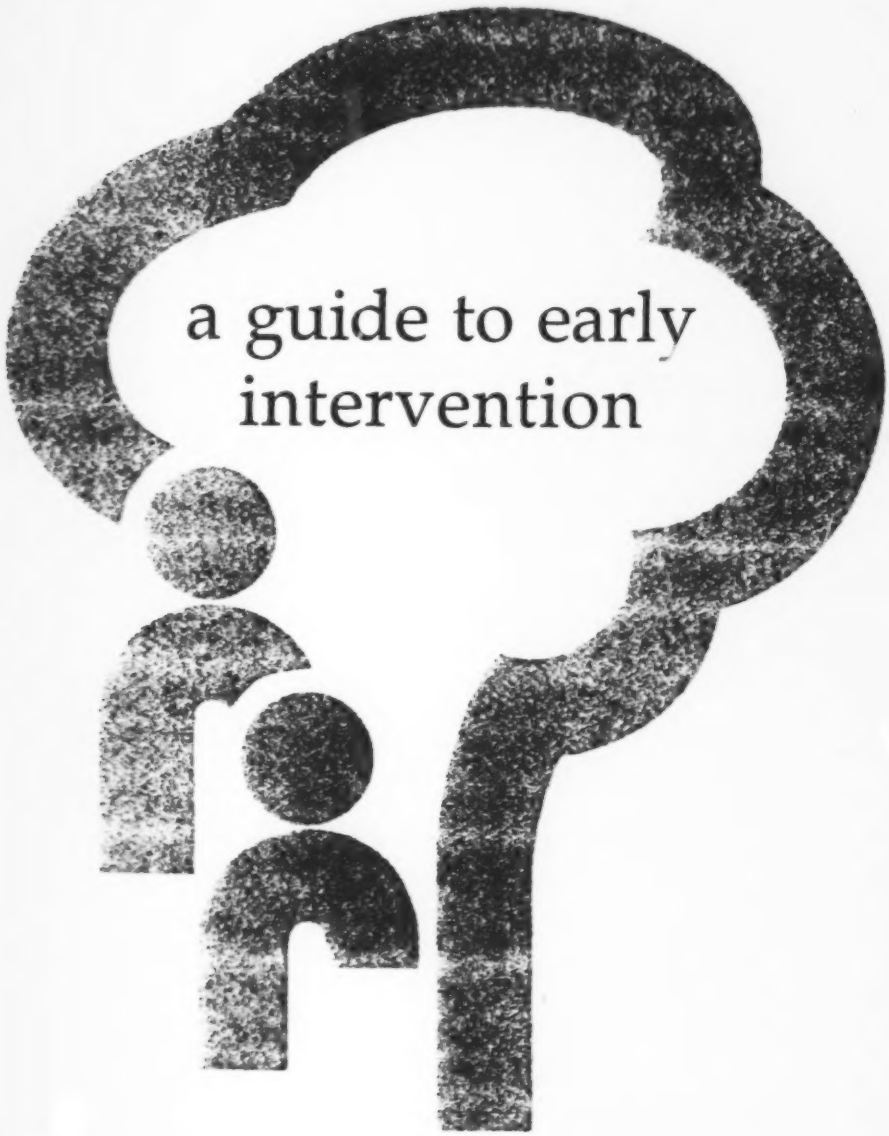

a guide to early intervention

A Resource for Families

EC 302434

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A GUIDE TO EARLY INTERVENTION

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Illustrations by Rocco L. Carsia

A Guide to Early Intervention was developed by the staff of Child Development Resources. CDR wishes to express appreciation to Andrea Quigley for her help.

PREFACE

Early intervention is a system of services for children birth to three who have special needs and for their families. Because early intervention is not a single service and because it will be different for each child and family based on their concerns and priorities, it can be a complicated system for families to understand. Child Development Resources developed this guide as a first step for families in understanding the early intervention system.

Child Development Resources, Inc., (CDR) in Lightfoot, Virginia, is a private, nonprofit agency that provides services for young children and their families and training for the professionals who serve them. CDR has won national recognition for the quality of its early intervention programs, for its commitment to family-centered services, and for its training and technical assistance to early intervention professionals throughout the United States. For more information about CDR, write or call:

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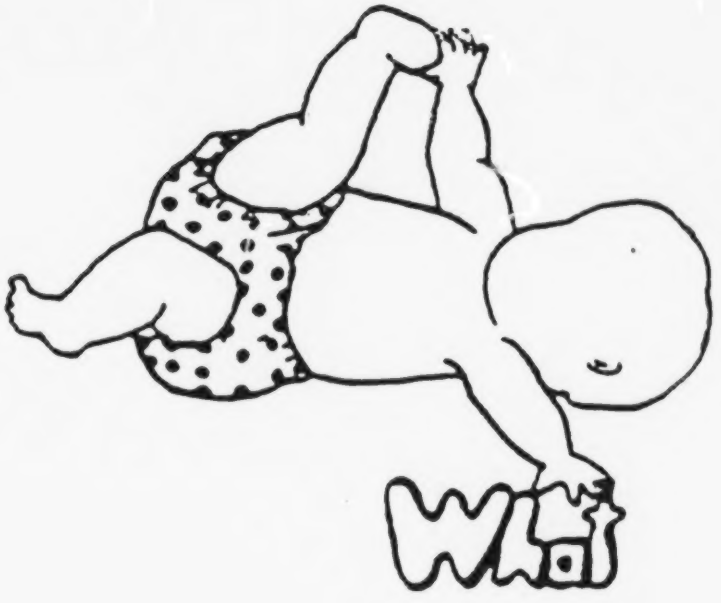
WHAT IS EARLY INTERVENTION?

Early intervention is a system of services for young children, birth to three years of age, and for their families. The early intervention system may sometimes be called the "Part H" program. Part H of the Individuals with Disabilities Education Act (IDEA) is the federal law that encourages states to serve infants and toddlers with special needs.

Early intervention is designed for children who have a disability, a delay in development, or who are at-risk for developmental delay. In early intervention, parents and professionals work together as partners. Each brings important information and skills to the partnership.

The agency responsible for early intervention is different in each state and early intervention services are provided by many different agencies, programs, and professionals in each community. If your child is eligible for early intervention in your state, federal and state policies help to ensure that your family gets the services you want and need.



WHY ARE THERE PROGRAMS AND SERVICES FOR FAMILIES AND BABIES?

- Working with some babies early in life helps to *prevent* problems in their development.
- Experience and research has shown that working with children with disabilities early in life helps reduce the effects of their disabilities.
- Early intervention programs and services help families with the practical and emotional problems that may come with having children with special needs or disabilities.
- Although many children learn to crawl, talk, and play without much help, some children need special help. Early intervention can help families grow more skilled at encouraging the development of a child with special needs.
- Early intervention programs and services can help families learn more about child growth and development and how to manage children's behavior.

WHOM DOES EARLY INTERVENTION HELP?

Each state has different regulations for deciding who can receive early intervention services. All states include:

- Children from birth to three years of age and their families
- Children with disabilities
- Children with health problems or other conditions that may cause delays in development
- Children who are slow in developing skills (developmentally delayed). Some states also serve children who are at risk for developmental delay.

Some families participating in early intervention have babies with developmental problems or delays. These problems may be small and easily helped. Other families have babies with problems that are so great they are called disabilities.

Although all these babies are very different from one another in the ways they will grow and learn, all of them have *families who care about them!*

WHO REFERS CHILDREN TO EARLY INTERVENTION PROGRAMS AND SERVICES?

Referrals often come from pediatricians and other physicians, from parents themselves, and from many agencies in the community that work closely with the early intervention system, such as:

- social services
- public health
- child evaluation clinics
- mental health clinics
- public schools
- hospitals
- Child Find
- other public and private agencies interested in young children

WHAT DOES EARLY INTERVENTION OFFER FAMILIES?

- An opportunity to become a member of a team. Being part of the early intervention team can help you in the exciting job of helping your child grow and develop.

- An opportunity to meet other families, formally through parent meetings, or informally, through program participation. Parent groups provide a time and place to exchange ideas and information, discuss problems, and try solutions.

- An opportunity to learn more about using community resources and services.

- Support for the difficult job of being a parent.

WHAT CAN FAMILIES OFFER EARLY INTERVENTION?

- Family members can serve in policy-making positions in public and volunteer organizations that serve young children with disabilities.
- Families can provide early intervention programs with information about services that are needed in the community.
- Parents can be advocates for their own child and other children in their community, their state and at the national level.
- Family members can help train of professionals who work with young children with disabilities.
- Family members can provide information that is helpful in evaluating early intervention programs.

Fenichel, Emily, & Eggbeer, Linda. (1990). Preparing practitioners to work with infants, toddlers and their families: Issues and recommendations for parents. NCCIP Task Advisory Board.

WHO PAYS FOR EARLY INTERVENTION SERVICES?

Early intervention services are funded by a variety of sources. Funds to support services may be a combination of federal, state and local tax dollars. Each state has its own system for paying for early intervention services. In some states, public schools are responsible. In other states, public health, social services, or mental health or mental retardation agencies are responsible. Public agencies may contract with non-profit agencies to provide early intervention services. Many early intervention programs receive support from organizations such as the United Way, local religious or civic groups, and from individual gifts. Parents can support services by telling charitable groups about early intervention and its needs.

Early intervention service providers may charge fees, often on a sliding scale for the same services. Private insurance and Medicaid payments may be used for some of these fees.

WHAT INFORMATION WILL THE EARLY INTERVENTION SERVICE PROVIDER NEED TO HELP YOUR CHILD?

- With your *permission* and *signed releases* a service provider may request medical records such as:
  - hospital reports of your delivery and your baby's birth
  - your baby's hospital, doctor, or health department records
  - your baby's immunization record

- A service provider may need information from specialists in order to plan an appropriate program for your child. These specialists may be a pediatric neurologists, a pediatric orthopedist, an audiologist, vision specialist, nutrition specialist, or others.

- To begin early intervention services, your child needs to have an evaluation/assessment. During the assessment, you and your family, together with other members of the assessment team will look for the things your child can already do, the new things your child is ready to learn, and how the team can work together to help your child learn. Because the needs of your child and family may change, an assessment may be done as often as every six months or as your child's needs change.

WHY DO WE NEED TO DO AN ASSESSMENT?

Your child has been referred for early intervention services because you and your family, your health care provider, or others who know your child have a question or concern about your child's development. You may already know that your child has a disability. Your child may be having problems in development, perhaps because of prenatal, delivery, or post-delivery factors. An assessment can help you answer your questions and will help the team decide if your child is eligible for early intervention services.

An assessment is a necessary part of planning early intervention services. It is an important time for you, your family, and other early intervention professionals to find out what your child can already do and what your child is ready to learn. What you and the other members of the early intervention team learn about your child during the assessment will help you work together to plan and choose the early intervention services that are most helpful to your family.

The assessment is a time when you can share information about your family's resources, priorities, and concerns related to your child's development and a time to let the other team members know how they can help. Before the assessment, an early intervention team member may talk with you or ask you questions in writing. These questions may help you think about your child's development, about his needs, and about your family's resources, priorities and concerns.

WHAT HAPPENS DURING AN ASSESSMENT?

The purpose of an assessment is to answer questions you and the other team members have about your child and to plan an early intervention program to meet your child's developmental needs. You may also want to let the other team members know about:

- your concerns and priorities- the things you want to happen for your child
- your resources- the things your family is already doing or able to do to help your child.

Parents are important members of the assessment team. You know more about your child than anyone else. You can help with the assessment by sharing what you already know about your child.

At least two other professionals will join you on the assessment team. Team members will be chosen based on your child's special needs. Each child's team may be different. You can help decide who should be part of your team. Your child's pediatrician and other health care providers are important team members. The whole team works together to assess your child's strengths and needs and to plan the program that will work best for your family.

In many programs, the assessment will be a playtime for your child. You will spend time with other members of the team playing with your child and watching her play in order to learn more about her development. Some team members may take notes to help them remember what they say during the assessment. They may use child assessment instruments to help them find out what your child can do already and what she is ready to learn. Anything another team member writes down during the assessment can be shared with you.

After your child's assessment, you and the other team members will have a chance to talk about the assessment. Time for parents to talk together with the other team members is an important part of the assessment. A safe play area and child care are often provided for your child by the team. You may want to talk over child care arrangements with the team before the assessment, so that you can participate comfortably in the planning time.

WHY DOES AN EARLY INTERVENTION PROGRAM NEED YOUR HELP IN THE ASSESSMENT AND THE IFSP PLANNING MEETING?

The early intervention team hopes to learn enough about your child during the assessment to answer some of the questions you and the other team members have and to decide if your child is eligible for early intervention and to plan early intervention services. You are an important member of the team. The practitioners need you to help plan the program that will work best for you and your family. Following the child's assessment, you and other team members have a chance to share ideas about your child's development.

Families play a central role in designing effective early intervention services through the IFSP-- the Individualized Family Service Plan. The IFSP is both a *process* and an *product*. It is the way you and the team will work together, *and* a written plan for your child. Most importantly, the IFSP is a *promise* to you and your child-- a promise that your resources will be recognized and built on, that your priorities and concerns will be addressed and that your hopes for your child will be encouraged and supported.

The assessment and the IFSP meeting are an important time for your family to think about the ways in which you hope your child will grow and change. It is the time to let other team members know how they can help you. The early intervention staff is available to provide you with information and support to help you with your decisions.

NOTE: A parent guide to the IFSP process is also available from Child Development Resources. An order form is in the back of this book.

WHY A TEAM?

Each member of the early intervention team has different training. Each professional can help the team understand how your child can grow and learn. *You* are a member of the team because you know more about your baby than anyone else.

Some parents may feel awkward or uncomfortable in the new role of *early intervention assessment team member.* You may ask yourself: What do these people want? What am I supposed to tell them? What if I don't want to talk about certain things? Remember that you are only expected to do and say what is comfortable for you. Each family creates their own on role the team based on what *feels right.* Just as all teams grow and learn together, you and your early intervention team will develop a way to work together that is comfortable.

WHAT HAPPENS DURING THE IFSP PLANNING TIME?

During the time for planning the IFSP you and other team members can share information about how your child is learning and growing and about the things you would like to change for your child and family. The decisions you make during this planning time will be put in writing in the Individualized Family Service Plan (IFSP). The plan will include the outcomes you would like for your child and the early intervention services you will have. The IFSP should also include the things your family would like to do to make the plan work. The IFSP will be completed within 45 days from the time your child was referred for early intervention services.

The IFSP is a flexible working plan. As your child grows and changes and as your family's concerns, resources, and priorities change, you can change your plan.

WHAT WILL BE IN THE IFSP?

The IFSP must contain:

- a statement of your child's present levels of:
  - physical development (including vision, hearing, and health status)
  - cognitive development (how a child thinks and learns)
  - communication development (how a child understands and uses sounds, gestures, and words)
  - social or emotional development (how a child plays and interacts with people)
  - adaptive development (how a child eats, sleeps, dresses, toilets)

- if you agree, a statement of your family's resources, priorities, and concerns related to enhancing the development of your child;

- the major outcomes to be achieved for your child and family, and the ways the team will measure:
  - progress toward the outcomes
  - whether changes in the outcomes or services are necessary;

- a statement of the specific early intervention services to meet the unique needs of your child and the family;

- a statement of how, where, and how often services will be provided and payment arrangements, if any;

- to the extent appropriate, a statement of the medical, prevention, and other services that your child needs, and, if necessary, the steps that will be taken to help your family get those services;
- a statement of how early intervention will be offered in your child's natural environment (where he would be if he did not have a disability);
- the date when services will start and about how long they will last;
- the name of the service coordinator who will be responsible for the implementation of the IFSP and coordination with other agencies and persons; and
- the steps to be taken to support transition as your child gets ready to leave early intervention services.

Sources: *P.L. 99-457 Regulations, 34 CFR Part 303, June 22, 1989 and Congressional Record, Part H of IDEA Re-Authorization, September 11, 1991.*

WHO MAY BE PROVIDING EARLY INTERVENTION SERVICES?

The service coordinator is a very important team member. A service coordinator is often the first person whom you will meet from the early intervention team. The service coordinator can help you decide whether or not your child should have an assessment and can help you plan for the assessment.

You and the service coordinator are two members of the early intervention team. The team may also include:

- other family members you choose
- a teacher/infant specialist/early childhood teacher
- a maternal and child health nurse
- a speech/language pathologist
- an occupational and/or physical therapist
- medical consultants
- a nutritionist
- an audiologist
- a vision specialist
- family therapists, social workers, educational, developmental or clinical psychologists
- professionals from other agencies
- an advocate, if you choose

HOW CAN THE SERVICE COORDINATOR HELP?

One person will be chosen from among the team as a service coordinator. The service coordinator may be any member of the professional staff, a teacher, an infant specialist, a speech therapist, an occupational therapist, a physical therapist, a nurse, a psychologist or social worker or any person on your team. You can help decide who is best able to meet your child's needs by sharing your thoughts with the other members of the team. Programs will work with you to match your needs with their staff resources in choosing a service coordinator.

The service coordinator's job is to make sure that all the early intervention services in your family's plan (IFSP) are provided and that they work well together. The service coordinator will help plan the assessment and the IFSP meeting. The service coordinator will help you find other services related to your child's development that your family may need. When the needs of your child or family change, the service coordinator can help you to change your IFSP. A service coordinator is able to:

- coordinate the evaluations and assessments
- help plan for and take part in developing, reviewing, and evaluating the IFSP
- help you identify available service providers
- tell you about advocacy services
- coordinate and monitor the delivery of early intervention services
- coordinate with medical and health care providers
- help to develop a transition plan to preschool services if appropriate.

Parents may receive training to help them do any of these tasks.

Sources: P.L. 99-457 Regulations, 34 CFR Part 303, June 22, 1989 and Congressional Record, Part H of IDEA Re-Authorization, September 11, 1991.

HOW CAN THE INFANT SPECIALIST OR TEACHER HELP?

The infant specialist or early childhood teacher is trained to know how to encourage your child's cognitive, social/emotional, and adaptive skills: that is how your child understands and takes part in the world around him and how he learns to care for himself. With you and others members of the team, the infant specialist or teacher plans a developmental program to help your child learn about the world of people and things around him.

HOW CAN A SPEECH/LANGUAGE PATHOLOGIST HELP?

A child *learns* to communicate and to talk. This does not always happen automatically. The first few years of life are the most important years for teaching a child to understand others and express herself. Children with disabilities or developmental delays may need special teaching methods to learn communication skills.

A speech/language pathologist is a person licensed and specially trained to work with children and to help parents develop special skills for teaching their children. The speech/language pathologist will assess your child's communication skills and, with the team, help plan a program for your child. This member of the team may also assess your child's ability to suck, swallow and breathe. These skills affect a child's ability to make sounds as well as to eat. Your child's hearing is also very important. Sometimes an *audiologist*, a person trained to evaluate hearing, may provide additional help with your child's assessment.

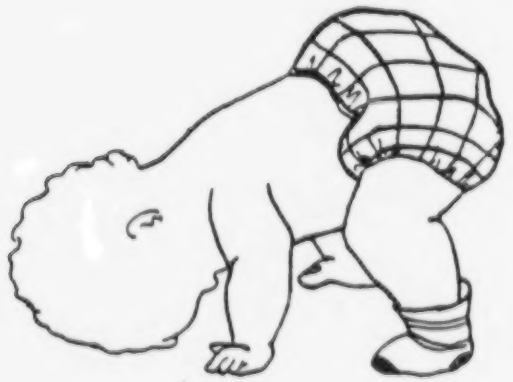
HOW CAN AN OCCUPATIONAL OR PHYSICAL THERAPIST HELP?

Walking, crawling, sitting up, and using fingers and hands to hold objects and to play are things that children learn. Physical and occupational therapists can work with you to help your child's muscles grow strong and to help your child use those muscles to move and play. Therapists have special training and are licensed and/or registered.

The therapist on the assessment team can help the team plan a program to encourage your child to:

- develop muscle strength
- use the muscles of his body to move and play
- use his senses, especially sight and touch, to understand the world
- hold and use objects and toys

Occupational and physical therapists can show you how to use special equipment, such as special chairs, shoes, or splints, that your child might need. A therapist may work directly with you and your child. A therapist may also work with you and other team members, teaching you how to use special techniques with your child to reduce or to prevent problems in motor development.



HOW CAN A SOCIAL WORKER HELP?

Part of the services that you may want or your child may need as part of the IFSP may include counseling, family therapy, crisis intervention or referral to other community resources. A social worker has special training and experience in providing these services.

A social worker can share information with your family about:

- families and the different ways family members interact with each other
- the effects of changes on families
- other services that your family might want or need to help your child

HOW CAN A PSYCHOLOGIST HELP?

Psychologists have special skills in counseling and behavior management. They are also trained in understanding a child's development and skills. Some states decide which children are eligible for early intervention by using scores on tests that must be done by a psychologist.

As a member of the assessment team, the psychologist can be helpful in:

- how your child is learning and exploring the world
- what special learning style your child uses
- what, if any, special learning problems your child may have
- how your child's development compares to that of other children

WHO ELSE MIGHT I MEET AT THE EARLY INTERVENTION PROGRAM?

Early intervention programs may serve as training centers for students or other people who want to observe and learn about early intervention. In many programs, volunteers add extra hands to keep your baby safe. If you leave your baby for program activities, the staff of professionals, aides, students and volunteers can give your baby the supervision and care he needs.

You may notice other visitors at the early intervention program from time to time. Parents are an important resource for people who want to learn about early intervention, how early intervention affects children and families.

WHAT EARLY INTERVENTION SERVICES MAY BE OFFERED?

There are a wide range of services available for you and your child in early intervention. In addition to assessment, IFSP development, and service coordination, you and your child may also receive specialized services related to your child's developmental needs. Services may be provided to your child in a group time or alone. Services can be provided at an early intervention program, in your home, or in the child care center where your child spends time. These services may include:

- individual therapies (physical therapy, occupational therapy, communication therapy)
- vision services
- audiological assessment and intervention
- special instruction
- health, medical and/or nursing services
- group or individual counseling, which can include other family members
- social services
- psychological services
- assistive technological devices and services (special equipment necessary to implement the IFSP)
- necessary transportation
- nutritional counseling

Other services may also be offered through interagency agreements in your state and community.

WHAT HAPPENS IN AN INFANT-TODDLER GROUP?

One way to provide early intervention services is in a group of children. Like all children, children with disabilities need to play with other children and to make friends. Many early intervention groups include children who do not have disabilities. If your child is already part of a group or you would like your child to be in a child care, preschool, or play group, an early intervention program can help your child's teacher understand and meet your child's special needs. A group time can be one way to teach your child the language, cognitive, social, self help, motor, and other skills included in the IFSP. Group time may also be a time that gives families relief, or respite, from child care.

WHAT DOES A PARENT GROUP DO?

Parent groups offer families an opportunity to meet other families with similar interests and priorities. Parents can support and encourage each other, share information, and learn about:

- child development
- the importance of your role in your child's growth and development
- the relationship between parents and other team members
- community resources
- legal rights to an appropriate early intervention education services

HOW CAN PARENTS HELP EARLY INTERVENTION SERVICES?

Parents are an important resource for early intervention programs for planning and carrying out quality services for young children.

- Your early intervention program needs your family to:
  - help plan, evaluate, and suggest changes in early intervention services
  - develop support for early intervention services
  - serve as advocates, policy-makers and trainers
- Other families need you:
  - as models in new and unfamiliar roles
  - for support and companionship
  - for information, ideas and solutions

WHY A HOME PROGRAM?

Early intervention services for your child are best provided in a natural setting. A natural setting is one where your child would spend time even if he was not having a problem in development. Early intervention programs often offer services at home because parents are their babies' first and most important teachers and because your home is your baby's most important learning place. There are many times and circumstances in which services can be and are provided in other settings, including your day care center, a play group, an early intervention program center, or even in a hospital or clinic. As part of your child's IFSP you will decide where your early intervention services will be offered.

Teaching and learning take place any time families and babies spend time together and babies come in contact with people and things. Early intervention professionals can help you use your time at home to teach your baby the things you most want her to learn in ways that will make teaching and learning easy for both of you. The place where you and your baby are most comfortable is the best place for your child to begin to learn.

WHAT WILL HAPPEN DURING HOME VISITS?

If you choose early intervention services at home, one person from the team will visit your home on a regular schedule. The home visitor will give you ideas about how to help your child learn new skills. You will have a chance to try these ideas in your home. The home visitor will help you find things you have in your home that you can use to help your child learn. He or she may bring other materials or toys for you and your child to try. Written suggestions may be left with you to try with your child.

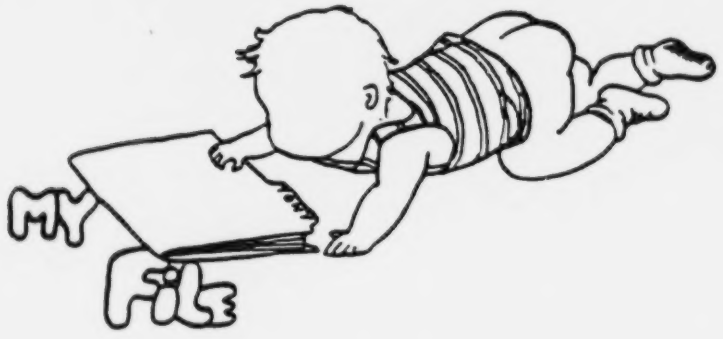
A home visit is also a time for you to express any concerns you may have or share information that is important to your child's plan. A home visit is another time and place a family and early intervention team member can work together and strengthen their relationship.

WHAT IS IN MY CHILD'S FILE?

Early intervention service providers keep information needed to plan your child's developmental program and record your child's progress. This file may include:

- referral and screening information
- team assessment reports
- Individualized Family Service Plans (IFSPs) with outcomes, objectives, activities, and services
- medical records
- correspondence
- the developmental scales or assessment instruments that are used to evaluate your child's development
- the service agencies involved with you and your child

You can request, and many service providers automatically send, reports or IFSPs written by the early intervention practitioners. You have a legal right to review your child's file at any time. Information from your child's file will be shared with other agencies or professionals *only with your permission*.



WHAT ARE PROCEDURAL SAFEGUARDS AND PRIVACY?

Parents are decision makers on the team. All of the information on the IFSP must be clear and explained to you completely. No information will appear in any written reports or in the IFSP without your permission and agreement. No service will be provided unless it is something you choose for your child and family and you provide your written consent.

You have many rights as the parent of a child receiving early intervention services. These rights are called *procedural safeguards*. All early intervention service providers must have written procedural safeguards. Because your rights are so important, your service coordinator must review them with you before the program or services begin and at least once a year thereafter. Please be sure you are given written information about your rights.

WHERE WILL MY CHILD GO WHEN HE LEAVES THE EARLY INTERVENTION SERVICE SYSTEM?

When you and your child no longer need early intervention services or when your child is close to his third birthday, the service coordinator will usually be the person to help you make other plans for him. Some children move to another special program while others go to nursery school, day-care, or Head Start. Some children need only a "check-up" in a few months to be sure that they are continuing to do well.

Plans to help you and your child make the change from early intervention to other services are called transition plans. A transition plan should be developed no later than three months before your child turns three.

WHAT KINDS OF PROGRAMS AND SERVICES ARE AVAILABLE FOR MY CHILD AFTER HIS THIRD BIRTHDAY?

- Nursery or Preschool

  A group of young children between three and five years old, who have a teacher to help them learn and play. Usually, these groups meet three to five days a week. Many nursery schools and preschools are happy to have children with disabilities in their classes.

- Child Care Center

  These centers are for the parent who is working or in school, offering a full-day program from early in the morning to late afternoon. Meals are usually provided. Some centers offer a sliding scale fee based on a family's income. Choosing the right child care program for your child is important. You may want to find a center that uses a developmental curriculum. Some early intervention programs also have their own child care centers.

- Family Day-Care

  Many working parents choose to leave their children in another person's home. This is called family day-care. Family day-care providers should not have more that five children in their homes. Choosing a good caregiver is important.

- Head Start

  Head Start, for children three to five years of age, provides experiences that help children from families with low incomes learn and develop. At least 10% of Head Start's space is reserved for children with disabilities. Some programs, called Parent Child Centers, serve children from birth and provide special family services.

- Resource Help

  Your child may not need to be in a special education classroom but may continue to need special help,such as speech/language, physical, or occupational therapy. If your child is eligible for special services, they are available through the public schools. Private, licensed therapists are also available through diagnostic centers, your own local hospital's therapy departments, or private practitioners. Your insurance company may be able to help you with any costs.

- Public Schools

  All states have programs for children with disabilities who are three years old or older. A special class or home program is offered by your public school system for children who meet the eligibility guidelines for your state. Information about these programs is available through your state Department of Education, your local public school special education program, and through your service coordinator.

SUMMARY

A Family Guide to Early Intervention is a first step in providing information to families. It describes early intervention services and defines the roles and responsibilities we each, parents and practitioners, have in this partnership. An understanding and respect for your family's concerns, priorities and resources is the foundation for your family's early intervention program. Team members will help and support you in making choices by sharing information, work with you to assess your child's needs, and provide services. As your child's needs change, your priorities, concerns and the services you want and need may also change. Your relationship with the early intervention team should help you find the best services for your child and family.

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